ANNUAL REPORT

2023

National MPS Society

Support for Families. Research for a Cure.

CONTENTS

National MPS Society
Support for Families. Research for a Cure.

MISSION

The National MPS Society exists to cure, support, and advocate for MPS and ML.

P.O. Box 14686
Durham, NC 27709-4686
877.MPS.1001
919.806.0101

MPSSOCIETY.ORG

Follow us!

Pictured on the cover: Spencer Laughlin (MPS IIIA)

As we celebrate the 50-year legacy of Katherine Burdine and Alice Teetsell Kalamar, founders of "Parents with MPS" (precursor of the National MPS Society), we are reminded of their pioneering spirit and unwavering dedication to the MPS community. Their vision and commitment continue to inspire us as we strive to be a beacon of hope for families. This year, we once again rose to the challenge, providing aid and optimism during difficult times. We want to express our deepest gratitude to our volunteers, donors, collaborators, and team. Your support is not just invaluable; it's how we can continue to make a real difference in the lives of those we serve.

Despite new challenges presented this year for clinical studies and struggling legislation for rare diseases, our devotion to supporting family programming and research remained steadfast. We continued our efforts by providing community webinars, teaching MPS outcomes, meeting with state health labs, and responding empathetically to grant requests. This ongoing commitment to research has not only provided reassurance and confidence to those we serve, but is also a testament to our dedication to our mission. Astonishingly, we have provided more than $2.1 million in direct programming and more than $21 million through our research program since 2000.

We are thrilled to share the success of our new Crossing Paths program, which has brought equitable access to MPS education and advocacy tools to underserved communities. This innovative inner-city outreach program, which visited Cleveland, OH; Denver, CO; Los Angeles, CA; Miami, FL; Paramus, NJ; and San Antonio, TX, has facilitated more than 200 face-to-face meetings between our team and community members. These interactions have not only fostered trust, friendship, and a shared learning experience, but laid the foundation for a more inclusive future.

We also continued to support adults with MPS and ML and their siblings in pursuing higher education. Twenty-eight scholarships were awarded through our Continuing Education Scholarship program. In addition, five grants were issued through the Jeffrey Bardsley Scholarship Fund; each recipient received a $5,000 award for excellence in academics. In 2023, 68 grants were issued through our family support and bereavement programs. This is one of our highest utilizations in a single year—illustrating the growing need for family assistance. Finally, the Society issued 44 conference scholarships to newly diagnosed families, families that have not yet attended a conference, those underserved, and adults with MPS and ML.

The 37th Annual Family and Science Conference, held in Bethesda, MD, was a resounding success. The conference hosted 425 attendees, including MPS families, industry partners, FDA and NIH representatives, and other key stakeholders. Incorporated this year was our first legislative advocacy conference since 2007. As we continue to build new roads with newborn screening and equitable access to healthcare,

we also challenged the FDA to consider science in relevant biomarkers as surrogate endpoints for clinical studies. The Society invited the EveryLife Foundation, Dr. Peter Marks, the Center for Biologics Evaluation and Research, and industry representatives to discuss the challenges of neuropathic diseases and drug development approval. Sponsor companies continued to struggle through clinical studies in 2023, facing significant trial challenges, FDA obstacles, economic challenges, and failed scaled business models, which have led to a shrinking U.S. landscape for studies.

Still, companies like Ultragenyx brought hope for the Sanfilippo A patient community. Their purchase of the global rights in 2022 to ABO 102, now UX111, verified that they are working hard to accelerate the approval of this gene therapy which has demonstrated positive outcomes. In addition, companies such as Denali Therapeutics, JCR Pharmaceuticals, and Orchard Therapeutics are developing therapies that will address blood-brain barrier issues.

We are proud of our achievements and are optimistic about the future. Thank you for your ongoing belief in serving our mission.

The growth of our research program led to the implementation of a new Research Committee, which will define areas of need and emphasis that both focus and encourage research in those areas and create pathways to investigators seeking funds. We are grateful for the continued funds of the Christa Armstrong legacy gift, and from the Sock-it 2 Hunter foundation for ongoing research support for MPS II. In 2023, the Society funded almost $675,000 in grants worldwide, a significant milestone in our research efforts. Also notable in research accomplishments was Terri Klein's presentation at the Society for the Study of Inborn Errors of Metabolism in Jerusalem on international registries with Sanofi, as well as Matthew Ellinwood's continued efforts in Delphi MPS II contributions and commentary for newborn screening.

2023 was a year to recognize outstanding achievements by researchers and clinicians in MPS and ML. We are deeply grateful for their dedication and contributions. Recipients included Joseph Muenzer, PhD, MD, who received the Legacy Award for Clinician; Mark Sands, PhD, who was honored with the Legacy Award for Research; and Ekatarina Wright, MD, who was presented with the President's Award. We also celebrated the recognition of Terri Klein, who received the prestigious Torch Award from Sanofi for her continued patient advocacy efforts in rare diseases worldwide. These individuals have made significant contributions to our cause, and we are proud to have them as part of our community.

We sum up 2023 as a year of scientific collaboration for biomarker relevance in MPS and the continued growth of serving an underserved population. We are proud of our achievements and are optimistic about the future. Thank you for your ongoing belief in serving our mission. Long-awaited treatments for Sanfilippo and Mucolipidosis II/III communities are finally coming into our sight. We will continue to strive to make a lasting difference in many lives for years to come.

Lisa P. Todd, chairman of the board

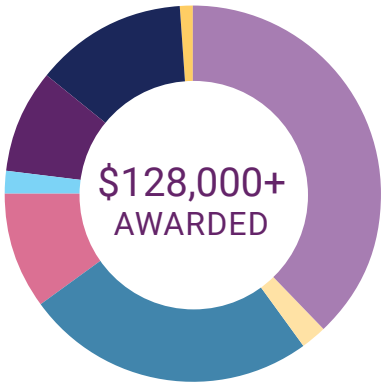
Terri L. Klein, president and CEO

Drs. Matthew Ellinwood and Peter Marks discuss the need for biomarker endpoints in clinical studies with an esteemed panel.

FAMILY SUPPORT

KRISTEN RUIZ (MPS IIIA) AND FAMILY

Kristen loves being outside, going on bike rides, and traveling with her family. As her illness progressed, it became almost impossible to do what she loved. Thanks to the Family Assistance Program, Kristen received a portable oxygen concentrator that has allowed her to regain some of that lost freedom.



- Continuing Education Scholarships
- Extended Hospitalization Relief
- Family Conference Scholarships
- Family Assistance Program
- Journey Assistance Program
- Medical Travel Assistance Program
- Bereavement Expense Program
- Regional Social Events

The National MPS Society's Family Support program continuously provides assistance to new and existing families. In 2023, more than $98,000 in scholarship and grant funding was provided to approximately 140 families and individuals with MPS or ML. By helping families obtain items such as medical wagons, oxygen concentrators, iPads, and sleep-safe beds, as well as assist with medical travel costs, our grants help make living with MPS and ML a little easier.

This year, the Family Support program helped 44 families attend the 37th Annual Family Conference, held in Bethesda, MD, where they were able to connect with other families and medical providers, and hear about current and upcoming research. We expanded our Pathways program and are now able to see more families virtually, in person, and by phone. Our social workers provide resources and support to families in many different areas, including mental health, medical care, coping, education, treatment options, clinical studies, and connections to other families and providers. This year we also launched a new regional program, Crossing Paths, where we traveled to six cities to meet with new and existing families and provide localized support. This program gives families the opportunity to interact and enjoy a day of fun, community, and support. We look forward to bringing this program to even more cities next year.

The Continuing Education Scholarship program continues to offer funding for higher education for individuals with MPS or ML, their parents, children, and siblings. In 2023, the Jeffrey Bardsley Scholarship program awarded $5,000 to five individuals diagnosed with MPS, and the Klenke-Kirch Sibling Scholarship program offered an additional $500 to two individuals to help support siblings.

Through a variety of initiatives, the National MPS Society's Family Support program offers resources, compassion, and community for families and individuals throughout all stages of their journey.

KYLE UNDERWOOD (MPS II)

Kyle has a love for adventure and life, and getting around is important to him. With vision and mobility issues, it can often be challenging to find the right transportation for him to travel to work and social events. Each time he gets in his car, there is a risk of straining his back or hips and falling. By installing step bars provided by the Journey Assistance Program, Kyle can easily get into the car without worry, and live life to the fullest. While it may seem like a small modification, it has a big impact on his quality of life.

$98,000+
PROVIDED TO FAMILIES AND INDIVIDUALS
through scholarships and grants

2023 HIGHLIGHTS

Continuing Education Scholarships

- Awarded $48,000 through five Jeffrey Bardsley Scholarships at $5,000 each and 23 Continuing Education Scholarships at $1,000 each.
- Awarded two Klenke-Kirch Sibling Scholarships (at an additional $500 each to the $1,000 Continuing Education Scholarship).

Extended Hospitalization Relief

- Funded five grants for a total of $2,500 to support individuals with MPS or ML who have experienced an inpatient hospitalization for a minimum of 30 days.

Family Conference Scholarships

- Funded 44 scholarships totaling $31,624, providing necessary financial support for families to attend the conference.

Family Assistance Program

- Funded seven grants totaling $12,939 to provide assistance items, including hearing aids, specialized tricycle, travel sleep-safe bed, portable oxygen concentrator, and outfitting a handicapped bathroom.

Journey Assistance Program

- Funded nine grants totaling $2,472 for items, including iPads, medical wagons, all-terrain stroller, vehicle modification, and step-through bicycle.

Extraordinary Experiences Program

- Costs associated with a special experience, such as a school trip or summer camp.

Medical Travel Assistance Program

- Funded 24 grants totaling $11,915 to help with out-of-town travel costs for non-recurring medical appointments.

Bereavement Expense Program

- Funded 23 grants totaling $17,272 to provide support for families experiencing the loss of a loved one with MPS or ML.

Regional Social Events

- Provided $855 for events held in Kalama, WA, and San Antonio, TX.

AARON SHARP (MPS I)

Aaron and his family traveled from Michigan to Minnesota for his annual bone marrow transplant follow-up appointments for Hurler syndrome. Funds from the Medical Travel Assistance Program covered travel and lodging costs to relieve some of the financial burden of these visits.

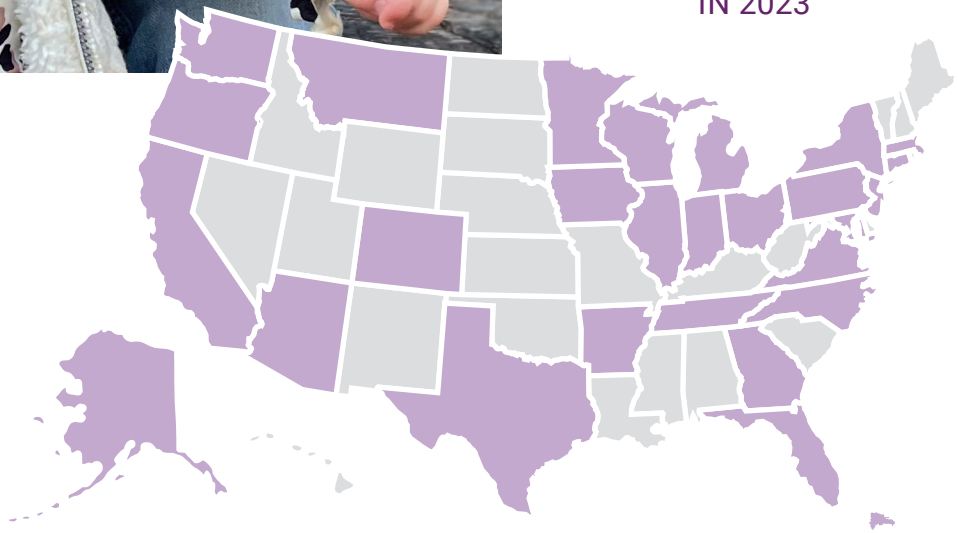
PATHWAYS

337
INDIVIDUALS SERVED
since program inception

GARRETT AND ALAYNA FELTNER (MPS IVA)

It was a long road to get an official diagnosis for our son, Garrett, but we finally got there in June 2023. We had so many questions and were so confused. Fortunately, we were able to get his ERT scheduled quickly, but still had no idea what we were doing. We learned of the National MPS Society from another parent in the infusion center and registered online. I was surprised when they reached out to me right away. They told me about the Pathways program and connected us with other parents. The amount of resources, advice, and support they provided us has been incredible. They advocated for our baby girl who currently is awaiting approval for treatment. Just to know that they stand with us during this diagnosis means more than they will ever know.

STATES SERVED
BY THE PATHWAYS PROGRAM
IN 2023



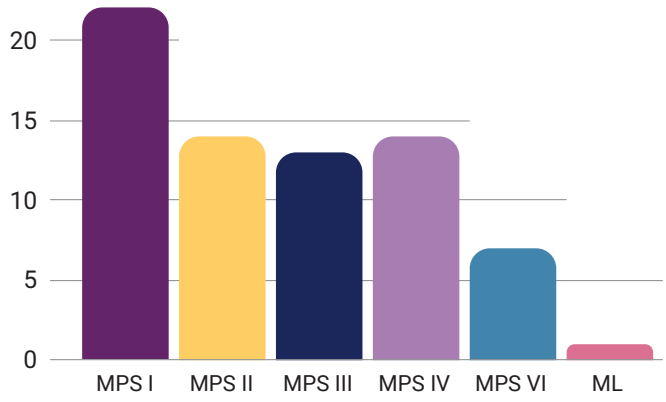
MPS Pathways
TRAVELING THE JOURNEY **TOGETHER**

The National MPS Society's Pathways program has served 337 individuals and families since its inception in 2017. Providing families with education and comprehensive support throughout the first year of diagnosis is its core mission. The Pathways Committee continually evaluates this program to ensure newly diagnosed families receive optimal support and connection to the larger community. In anticipation of program growth due to increased newborn screening and Society outreach, a search ensued for the addition of a care manager, who began in early 2023.

Newborn screening efforts have proved successful in identifying children sooner so they may benefit from earlier treatment and intervention. This increase has been evident in the MPS I population and soon should become more evident in the MPS II population as more states begin to screen. The Pathways program is ready to serve these families through confirmatory testing and beyond.

A major achievement this year was the launch of the Crossing Paths program. The challenge of increasing health equity for the unserved and underserved in the MPS and ML community was met with the creation of events in thoughtfully identified areas of the country. One of the guiding principles for this new program is the belief that all families should have the same access to information, resources, connection to experts, and consideration for clinical trials. With great enthusiasm, these events have successfully reached new families who will now benefit from the Society's support.

SYNDROME TYPES
OF 2023 PATHWAYS INDIVIDUALS



2023 HIGHLIGHTS

- Provided Pathways program education, support, and resources to 71 newly diagnosed individuals from 59 families.
- Conducted visits with 54 individuals and families in 18 states.
- Served 337 individuals through the program since inception.
- Offered 10 support groups attended by 34 families.
- Identified 11 new diagnoses resulting from newborn screening for MPS I. One sibling additionally diagnosed through cascade testing.
- Launched the Crossing Paths program with six events in six states striving to reach underserved MPS and ML families who could most benefit from the National MPS Society's programs and support.
- Built ongoing relationships with industry partners to better collaborate and serve the MPS and ML community.
- Connected with additional families at the Annual Family Conference in Bethesda, MD, and moderated the SPIRIT Conference, which brought applicable programming to adults with MPS or ML.
- Accompanied families to advocacy visits in Washington, DC, to promote key pieces of legislation to benefit the rare disease community.

ADVOCACY

114
ADVOCATES MET WITH
143 LEGISLATORS
during virtual and in-person visits

Pictured L to R: Astrid Weber and Harrison Weber (MPS I); Stacey Montgomery and Amy Downen; Zachary Thomas, MPS I advocate for newborn screening

Advocacy efforts of the National MPS Society extend beyond legislative corridors into the very heart of the communities we serve. In 2023, we expanded our advocacy programs, working with state leaders and residents to voice concerns and influence decision-making processes.

Initiatives include the Society's first legislative conference in 17 years, held in Bethesda, MD. Through workshops and strategic partnerships, we provided a platform for the FDA, NIH, EveryLife Foundation, and passionate advocates making tangible differences. Topics addressed included regulatory and policy hurdles on the path to optimal diagnosis and treatment through newborn screening, and equitable access to care. Peter Marks, MD, PhD, discussed the importance of the FDA working with key stakeholders in clinical studies for rare diseases and the importance of biomarkers as surrogate endpoints.

At the heart of our mission lies a steadfast commitment to advocating for policy changes that promote social equity and justice. In 2023, we successfully lobbied a clear indication of our unwavering dedication. Our growing Speaker's Bureau program hosted two essential visits with Capitol Hill legislators in February and October. Our dedicated team worked tirelessly to engage with policymakers, organize community forums, and launch awareness campaigns. These efforts have resulted in legislative success, and heightened public awareness and support for inclusive policies. Our advocacy work continues to be a driving force in creating systemic change that benefits the most vulnerable in our society. Last year, 114 advocates hosted meetings with 143 legislators around the country, a testament to the widespread support for our cause.

2023 HIGHLIGHTS

- Provided successful written testimony at Advisory Committee on Heritable Disorders in Newborns and Children meetings for the N=1 rule. Recognizing pilot studies to identify a patient with a rare disorder should not be the burden of the Recommended Uniform Screening Panel (RUSP) nomination process.
- Facilitated virtual Capitol Hill meetings in February and in-person visits in October with 114 advocates meeting with 143 legislators to advocate for newborn screening, increased NIH funding for MPS and ML diseases through the appropriations bill, and recruited Rare Disease Caucus members. Six members of Congress and the Senate met directly with their constituents.
- Attended in-person Capitol Hill visits in October with 68 advocates meeting with 72 legislators.
- Continued Newborn Screening Committee oversight of MPS RUSP alignment language and state grassroots efforts for all MPS disease screening. Authorized the committee to sponsor companies and other lysosomal disease leaders.
- Participated in Rare Disease Legislative Advocates' Rare Across America virtual Capitol Hill visits in summer 2023. Terri Klein made first initial contacts with leaders of the Cherokee Nation to open discussions for indigenous community awareness.
- Supported Congressman Mark DeSaulnier (D-CA) sponsored appropriations language with a request for an additional $17 million allocated to research for MPS and ML diseases.
- Maintained our Rare Hub space in Washington, DC, at the EveryLife Foundation offices and participated in quarterly working group meetings.
- Worked with Rare Disease Advisory Council state committees on their advocacy formation and oversight.
- Supported the following legislation and signed onto letters for:
  - H.R. 482/S. 350—**Newborn Screening Saves Lives Reauthorization Act**
  - H.R. 2666—**MVP Act—Medicaid VBPs for Patients**
  - H.R. 1730/S. 670—**Speeding Therapy Access Today (STAT) Act**
  - H.R. 5585/S. 3819—**Advanced Research Projects Agency for Health (ARPA-H)**
  - H.R.4472/S.373—**Better Empowerment Now to Enhance Framework and Improve Treatment (BENEFIT) Act**
  - H.R. 6094—**Providing Realistic Opportunity To Equal and Comparable Treatment for Rare Act (PROTECT Rare Act)**
  - H.R. 1350 and H.R. 1805—**Cameron's Law and Leo's Law**—restoring increased tax incentives to 50% and removing barriers for rare drug exclusivity incentives.
  - **Medicaid and Children's Health Insurance Program (CHIP) Managed Care Access, Finance, and Quality (CMS–2439–P)**
  - RUSP language support for state reviews.
- Attended the following advocacy and networking conferences: *19th Annual* WORLD*Symposium™; American Society of Gene & Cell Therapy Policy Summit; National Organization for Rare Disorders Summit; Association of Public Health Labs Annual Meeting*.
- Continued efforts with rare disease working group and BioMarin on EPICrd Act—ensuring parity through individualized care for rare disorders.
- Participated in quarterly newborn screening and diagnostic meetings held by EveryLife Foundation.
- Hosted first Youth Advocacy Workshop where 14 youth advocates and their families participated in a program geared toward understanding the legislative process and how their stories can impact it.

Scott Hopkins, Helen Allison, and Lynn Hopkins bring MPS awareness to Washington, DC

FUNDRAISING

GARABITO 5K FUNDRAISER

The National MPS Society reached new donors and increased membership throughout 2023. Donors continued to inspire and believe in the Society by helping us reach historical funding of more than $348,000 for the Annual Fund, which provides crucial funding for operations and oversight of our mission. Last year, we developed new Planned Giving materials and hosted a legacy event at our family conference in Bethesda, MD. The Maritime Gala, held in Napa, CA, with 150+ attendees, raised more than $210,000 for family support and research.

The Fundraising Committee continues to create unique opportunities to share the journey of MPS and ML. Future efforts will focus on developing a Capital Campaign and growing our Planned Giving program. The committee recognizes the importance of using our skills and energy to ensure we progress with sustainability and thrive to support our mission.

$560,000
RAISED THROUGH
FUNDRAISING EVENTS

2,750+
ACTIVE MEMBERS
of the National MPS Society

Fundraisers

2023 Maritime Gala, hosted by the National MPS Society

American Golf Foundation, in honor of Michelle Hopkins, hosted by Hugo Van der Moer

ARC Fundraiser, hosted by ARC Committee

Big Bake for MPS and ML, hosted by the National MPS Society

Bohley Family Fundraiser, in honor of Jacob Bohley, hosted by Alicia Bohley

Care for Rare: Maverick's Walk to a Cure, in honor of Maverick, hosted by Jasmine Cameron

Coin Drive - Aleyah, in honor of Aleyah Smith, hosted by Charity Smith

Concert for a Cure, in memory of Ryan Mask, hosted by Dorothy Mask

Crop for Rachel, in memory of Rachel Dodson, hosted by Jim and Michelle Dodson

Do It Fore Dan, in memory of Danny Miller, hosted by Ray and Amy Miller

Garabito Fundraiser, in honor of Emilio Garabito, hosted by Katherine Garabito

Holland Family Fundraisers, in honor of Spencer, Madison, and Laynie, hosted by Steve and Amy Holland

Hopkins cabi Party, in honor of Michelle Hopkins, hosted by Lynn Hopkins

Jaela's Courage, in honor of Jaela Hernandez, hosted by Michelle Anjela Yumul

Jaxon Trappe 4H Fund, in honor of Jett Trappe, hosted by Claire and Jon Trappe

Keller's 5K For MPS, in honor of Keller Blakeley, hosted by Clinton and Lindsey Blakeley

Kramer Chili Cook-Off, in honor of Marcus Kramer, hosted by Beth Kramer

Lacerta 5k, hosted by Courtney Rouse and Lacerta Therapeutics

Lilah's Lemonade Stand, in honor of Lilah Mueller, hosted by Kimber Heiling

Littlest Warrior Fundraiser, hosted by Michelle Sullivan

Long Beach Race for Rare, hosted by the National MPS Society

Loren's Birthday Fundraiser, in honor of Loren, hosted by James and Kimberly McClelland

Million Dollar Bike Ride, hosted by the National MPS Society and University of Pennsylvania's Orphan Disease Center

Napa Race for a Cure, hosted by the National MPS Society

Penny Pitch, hosted by Coldwater Exempted Village Schools

Post Office Café Run, in memory of Mark and Casey Lessing, hosted by Mark and Joan Lessing

Raleigh Run For Rare, hosted by the National MPS Society

Ryan Golf Scramble, in memory of Ryan Kapes, hosted by Carl Kapes

Spooktacular, in memory of Dorian and Wynn Johnson, hosted by Mercedes Ramirez Johnson

Stevens' Fundraiser, in honor of Meekel Stevens, hosted by Marla Stevens

Super Bowl Fundraiser, in honor of Adam Brennan, hosted by Mary Beth Brennan

Team Nora, in honor of Nora Spring, hosted by Leanne and Trevor Spring

T-Shirt Fundraiser, in honor of Blayne Nash, hosted by Courtney Nash

Terri Klein received the prestigious Torch Award from Sanofi for her continued patient advocacy efforts in rare diseases worldwide.

2023 HIGHLIGHTS

- Maintained four-star rating from Charity Navigator, representing sound fiscal management and commitment to accountability and transparency. This "exceptional" designation differentiates the Society from its peers and demonstrates to the public it is worthy of their trust.
- Supported an active membership roster of more than 2,750 members.
- Raised approximately $560,000 through virtual walk, run, and other fundraising events.
- Hosted four national run events in Raleigh, NC; Napa, CA; Long Beach, CA; and Long Island, NY.
- Raised more than $30,000 for MPS and ML research through the University of Pennsylvania's Million Dollar Bike Ride.
- Raised $348,424 through the 2023 Annual Fund campaign, chaired by Mercedes Ramirez Johnson.
- Raised more than $210,000 at the Maritime Gala in Napa, CA.
- Hosted 62 Courage Pages (customized, informative family web pages for awareness and fundraising) on the Society's website.
- Received Combined Federal Campaign application approval.
- Hosted the National MPS Society's fourth annual Big Bake for MPS and ML.

FUNDRAISING *(CONTINUED)*

Champion Circle

(monthly giving program)

Fernanco Armendariz
Colleen Arni
Robert Astamendi
Carole Barnhardt
Melany Bjorkman
Marie Blumeier
Claudina Bonetti
Marc Brdar
Michael Clawar
Margaret Cohen
William and Edna English
Teresa Everett
Robert and Melanie Franko
Shirley Hall
Steve and Amy Holland
Steve Holley
Jennifer Hutcheson
John Iannelli
Christine Jocoy
Brian and Rebekah Klutz
Cynthia Kraft
Theresa Leggett
Lauren Louison
Wynona Maxwell
Donny and Molly Merrill
Greg and Jennifer Mincks
Carik Moirrison
Susan Murphy
Joshua and Kathy Nay
Thomas Patterson
Linda Perrella
Lori Phillips
Samuel Ramsey
Mary L. Rich
Mark and Karen Sackett
Edward Schultz
Riddhi Shah
Jared Shelton
Mike and Barbara Smith
Michael and Angela Sochacki
Heidi Sosinski
Jeremy and Rena Stearns
Jack Swepston
Anne Tremege
Leslie Urdaneta
Alisa Vitello
Todd Waddell
Kim Whitecotton
Rick and Dawn Williams
Raymond Zechender





Highlighting National MPS Society fundraising events

Facebook Fundraisers

Lee Ann Adams
Sabrina Adams
Sierra Alexis
Melissa Anderson
Terra Campbell Anderson
Dana Armstrong
Ashley Avery
Avery's Army
Shaun Bach-Haynes
Charlotte Barrett-Weber
Amy Becker
Mandy Bellassai
Rachel Bess
Rebecca Trivette Bivens
Darryl Block
Melanie Block
Cenia Blount
Misty Crawford Bonner
Martha Rooks Booth
Mary Case
Diane Cloutier
Haley Compton
Kaitlyn Corwin
Stephanie Cozine
Carla Halk Crain
Barbara Ann Cullere
Cassie Dearman
Wilma Dickerson
Ally Dickson
Kailey Dina
DjMPSWarrior
Amy Phillips Downen
Amanda Duggan
Jennifer Lee Eickman
Melinda Elliott
Sherry Engen
Wayne Eppehimer
Patricia Espinal
Lance Filby
Diana Force
Elizabeth Fry
Jolene Funderburk
Julie Garrison
Michelle Gordon
Cassidy Gosey
Rebecca Green
Chey Halk
Taylor Harvey
Susan Healy
Kimberly Heiling
Cassie Hester
Jaelynn Hill
Lela Holbrook
Robin Anne Hord
Whitney Lynn Huntington
Amanda Johnson
Madelyn Johnson
Sherrie Clinton Johnson
Dianne Kelley
Joshua Kidwell
Kris Klenke
Cindy Owens Knight
Lisa and Dave Knight
Jenn Zurek Kozlowski
Michele Krause
Andrea Marie Lancaster
Nona Leon-Guerrero
Carly Lowder
Cheryl McGregor
Amelia Catherine McHugh-Rush
Viviana Medina
Eric and Vicki Merril
Amber Mongan
Hayden Murphy
Monika Nelis-Dupont
Megan Nicole
Shaun Noble
Tommy O'Brien
Marla Jane Parkman
Melissa Rachunek-Zielonka
An Rafferty
Nancy Davis Ramsy
Kathryn Reay
Julia Rice
Gabrielle Rivas
Valerie Roth
Krizia Ruano
Taylor Ruelas
Melissa K. Runyon
Bonnie Schwab
Erin and Spencer Shea
Shannon Smith
Kristin Soliz
Heather Novah and Josiah Bubba Stephens
Sara Stuber
Beverly Peebles Temple
Brooke Thomas
Gina Crown Torrans
Leslie Urdaneta
Emily V. Viti
Daisy Vasquez Vogt
Phuong Vuong
Christi Wadle
Nancy Wain
Denise Walters
Sheri Wise
Anjela Yumul
Noah Zimmerman

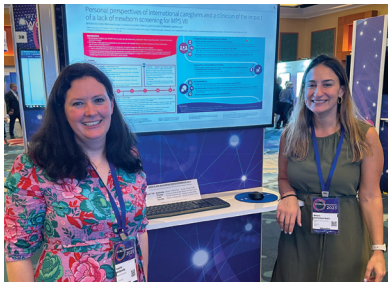
COMMUNICATIONS

The National MPS Society provides information and connections to members and stakeholders across multiple channels. Printed publications, social media, electronic communication, and other avenues enable us to deliver content to those benefiting from the educational and communications material shared.

We remain a leader in mucopolysaccharidosis and mucolipidosis expertise, offering educational materials, including syndrome booklets, resource guides, and fact sheets. These resources are developed for distrubtion through our website, and are available for clinicians to share with patients and families. We assess the MPS and ML community's informational needs and increase awareness of MPS, ML, and allied rare diseases. Our primary goals are to bring awareness to MPS and ML and provide the information necessary for effective, comprehensive care and management for those affected by these diagnoses. Most importantly, we strive to create a sense of community among families, care providers, and our valued stakeholders who all play an important role in our shared journey.

The Adult Resource Committee and the Communications Committee joined forces in engaging our community in celebration of International MPS Awareness Day (May 15). Keeping with the theme of the National MPS Society's Maritime Gala, our community enthusiastically submitted photos to create vibrant social media profile frames. It was inspiring to see hundreds of supporters across Facebook, Instagram, and Twitter (X) proudly display our messaging and share their smiles for all to see.

Michael Whitaker (MPS II)



Leslie Urdaneta and Belen Gonzalez Sutil

Last winter Leslie Urdanta, director of Family Support, was invited by Ultragenyx to collaboratively present a scientific abstract at WORLDSymposium™ *2023, the annual research conference dedicated to science, research, and clinical trial developments for lysosomal diseases.*

2023 HIGHLIGHTS

- Launched new website featuring more robust capabilities, increased translation functionality, and improved accessibility features to increase ease of navigation.
- Teamed with Casa Hunter to update and translate many of our syndrome and care-specific booklets for Spanish-speaking families and care providers.
- Published monthly *eCourage*, the Society's electronic newsletter, featuring stories about our members, news pertaining to rare disease developments, and celebrating the achievements and outreach of our volunteers, staff, and board of directors. A print edition of *Courage* is sent to members twice a year as well.
- Created and managed the content and promotion of special events hosted by families (fundraisers, run/walks, The Big Bake for MPS and ML), and events hosted by the National MPS Society, such as the Maritime Gala held in California in May.
- Publicized information on legislative action alerts, fundraising opportunities, other rare disease organizations' educational webinars, and opportunities open to the public for those with MPS or ML and their families.

RESEARCH GRANTS

One of the three major tenets of the Society is research. Finding cures and improved therapies for all of the syndromes is a primary goal. Grant funding, research partners, and collaboration ensure key efforts toward a better future for all those affected by MPS and ML.

In 2023, the National MPS Society's research program built upon the three annual defined grant submission cycles (Cycles I–III) with the implementation of a new grant submission portal (Proposal Central). The Society, with the continued assistance of the Scientific Advisory Board Guidance Committee, continues to define areas of need and emphasis that both focus and encourage research in those areas.

The 2023 combined total of both newly approved and past funding commitments totaled $674,242. This sum includes allocations for new competitive research awards of $632,709 with the balance spent on continued funding for previously awarded multi-year grants. Total research allocations disbursed toward these 2023 awards is $399,242. This total also includes $30,000 of Society research funds leveraged through the Orphan Disease Center of the University of Pennsylvania in our partnership with the Million Dollar Bike Ride to fund a total of $57,645 in research. Notable again this year was the continued support for MPS II and MPS II relevant research areas, totaling $41,533 in ongoing research commitments, provided from the Christa Armstrong Legacy Gift.

$674,242
COMBINED TOTAL
of newly approved and past funding commitments

Emily Lieber, friend of the Marinoff family and fellow parent of a child with Hunter syndrome, was approached by Road Scholar Transport to create huge wraps for their trucks featuring photos of Ethan Lieber and Aiden Marinoff to raise awareness of MPS II. The Marinoff family's Sock-it 2 Hunter foundation made a $75,000 donation last year to the National MPS Society to fund Hunter syndrome research.

KYLIE RANSOM (MPS VII)

Despite having two rare diseases, Kylie isn't letting anything stop her from living her life to the fullest. In between school, infusions, and dozens of doctor's appointments, Kylie loves being outside. She tends to the bugs that live in her bug house, jumps rope, and whenever her parents are available, rides her bike. However, she outgrew the bike and her tight hips and scoliosis brace made getting on and off difficult. The Society's Journey Assistance Program provided a new bike for Kylie that is designed as a step-through, so instead of having to swing her leg over the back, she can step across in front of the seat. Now that she is on a properly sized bike, she can enjoy benefits like going faster with larger wheels and multiple gears.

Innovation is driven by the work of our MPS and ML II/III research community. Their dedication and commitment to our shared mission make possible the treatment and outcome improvements of the future.

SOCIETY RESEARCH FUNDING

Competitive Program in Innovative Research Awarded in 2023

2022 Cycle III Grants

(Awarded June 1, 2023)

Tier II: $50,000 for a one-year MPS VI/ general research award to Dr. Lachlan J. Smith as a competitive renewal

The University of Pennsylvania, Philadelphia, PA, USA

Expansion of a Research Colony of Mucopolysaccharidosis VI Dogs

Tier I: $100,000 for a two-year MPS VIA general research award to Dr. Nicola Brunetti-Pierri

The Telethon Institute of Genetics and Medicine, Pozzuoli (Naples), Italy

Understanding the In Vivo *Consequences of GALNS Pathogenic Variants*

Tier I: $100,000 for a one-year MPS IVA/general research award to Dr. Katerina Kucera

RTI International, Research Triangle Park, NC, USA

Validation of a Multiplex Assay for Implementation of Newborn Screening for Mucopolysaccharidoses

Tier II: $50,000 fellow-initiated research for a one-year MPS IVA award to Betul Celik (Dr. Shunji Tomatsu, mentor)

The Nemours Foundation, Wilmington, DE, USA

Bone Targeting Lentiviral Gene Therapy

Tier II: $50,000 for a two-year general research award to Dr. Margret L. Casal

University of Pennsylvania, PA, USA

Odiparcil, Substrate Reduction Therapy to Treat MPS VI in a Canine Model Mucopolysaccharidosis VI

2023 Cycle I Grants

No offering was made for the 2023 Cycle I to allow for the implementation of the new grant application review, award, management, and reporting platform Proposal Central.

2023 Cycle II Grants

(Awarded Dec. 1, 2023)

Tier I: $100,000 for a one-year MPS III/general research award to Dr. Stephanie Cherqui as a competitive renewal. Awarded in 2023, with funding dispersed in 2024.

The University of California at San Diego, San Diego, CA, USA

Treating Mucopolysaccharidosis Type IIIC with Hematopoietic Stem Cell Gene Therapy

Tier II: $50,000 for a one-year general research award to Dr. Bamidele Kammen, Awarded and funded in 2023.

The University of California, San Francisco, San Francisco, CA, USA

Diffusion Tensor Imaging as a Non-Invasive Way to Analyze the Function and Anatomy of the Growth Plate in MPS IVA and VI

Tier I: $100,000 for a one-year ML/ general research award to Dr. Patricia Dickson. Awarded in 2023, with funding dispersed in 2024.

Washington University in St. Louis, St. Louis, MO, USA

Brain-Directed Gene Therapy for Mucolipidosis II/III with S1S3 Phosphotransferase

Second-Year Grant Award Funding Disbursed in 2023

$41,533 for year two of a MPS II Christa Armstrong legacy award to Dr. Liz Braunlin

University of Minnesota, Minneapolis, MN, USA

MPS Aorta

2023 Resource and Partnership Awards

$27,709 for a resource award to Dr. Jodi D. Smith

Iowa State University, Ames, IA, USA

Maintaining the Canine MPS Model Research Resource

$25,000 multi-syndrome general MPS award to the Lysosomal Disease Network

University of Minnesota, Minneapolis, MN, USA

The Neuroimaging Core NIH Project

The Orphan Disease Center

(Awarded February 2024 from funds raised at the 2023 Million Dollar Bike Ride)

$57,645 (Million Dollar Bike Ride & $30,000 from National MPS Society funding) to Dr. Manor Yehoshua

Sheba Medical Center, Ramat Gan, Israel

Antisense Oligonucleotide as Substrate Reduction Therapy for Mucopolysaccharidoses Type III

SUMMARY FINANCIAL REPORT

The financial information below has been summarized for the year 2023. The Society is a 501c3 nonprofit public charity. The complete audited financial statements and IRS Form 990 are available on our website or upon request.

Financial Position

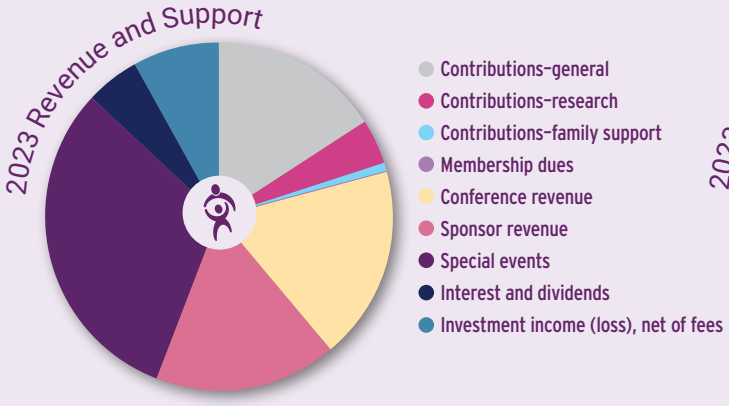
Assets	
Current Assets	
Cash and cash equivalents	$ 714,321
Investments	1,624,945
Prepaid expenses	34,545
Interest receivable	9,971
Total Current Assets	2,383,782
Fixed Assets, Net	
Furniture, fixtures & equipment	6,868
CIP—Website	30,564
Total Fixed Assets	37,432
Other Assets	
Operating leases right of use assets	186,849
Investments—restricted for purpose	267,278
Investments—restriced in perpetuity	1,138,568
Total Other Assets	1,592,695
Total Assets	$ 4,013,909

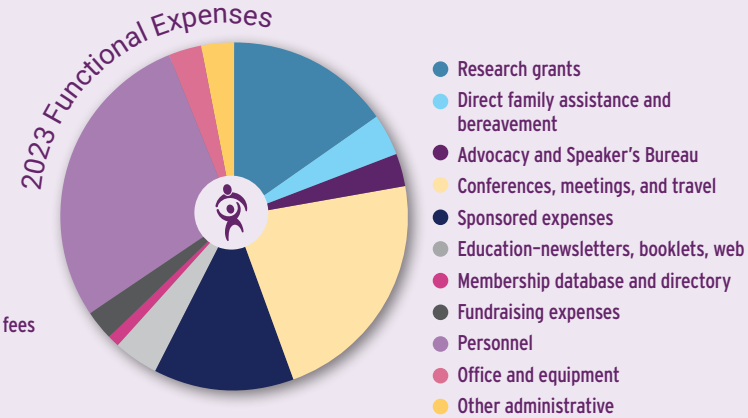
Current Liabilities	
Accounts payable	$ 6,763
Grants payable	50,000
Accrued salaries/vacation	38,541
Current portion of operating lease liabilities	46,776
Total Current Liabilities	142,080
Long-Term Liabilities	
Operating lease liabilities	144,011
Net Assets	
Without donor restriction	
Undesignated	1,036,149
Designated	629,296
With donor restrictions	
Purpose restricted	923,805
Perpetual in nature	1,138,568
Total Net Assets	3,727,818
Total Liabilities and Net Assets	$ 4,013,909

2023 Statement of Activities

Revenue and Support	
Contributions	
General	$ 401,837
Research	110,532
Family support	28,512
Membership dues	2,150
Conference revenue	451,952
Sponsor revenue	440,500
Special events (net of $110,841 direct expenses)	797,657
Interest and dividends	124,182
Investment income, net of fees	211,219
Total Revenue and Support	$ 2,568,541

Functional Expenses	
Research grants	$ 419,242
Direct family assistance and bereavement	120,609
Advocacy and Speaker's Bureau	82,142
Conferences, meetings, and travel	606,189
Sponsored expenses	372,126
Education—newsletters, booklets, web	121,250
Membership database and directory	39,831
Fundraising expenses	70,968
Personnel	787,013
Office and equipment	80,671
Other administrative	71,885
Total Functional Expenses	$ 2,771,926
Change in Net Assets	$ (203,385)





2023 CONTRIBUTORS

In 2023, the National MPS Society was able to provide support to families and funding for research because of the generosity of the following individuals, families, foundations, companies, groups, and fundraising events.

The board of directors thanks you for your dedication. The Society makes every effort to recognize our supporters through *eCourage* and this Annual Report. The following list represents all donations received in calendar year 2023. If your name is not listed, we apologize and ask that you contact us. If we received your donation in 2024, you will be recognized in the next Annual Report.

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maureen.cote@mpssociety.org

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nicole.bennett@mpssociety.org

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stephanie.cozine@mpssociety.org

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tamara.cullere@mpssociety.org

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patricia.espinal@mpssociety.org

Amy Holland (MPS I parent)
amy.holland@mpssociety.org

Scott Hopkins (MPS I parent)
scott.hopkins@mpssociety.org

Mercedes Johnson (ML II parent)
mercedes.johnson@mpssociety.org

Carl Kapes (MPS IIIA parent)
carl.kapes@mpssociety.org

Sheri Lueb (MPS IVA adult)
sheri.lueb@mpssociety.org

Jason Madison (MPS II adult)
jason.madison@mpssociety.org

Stacey Montgomery (MPS IIIB parent)
stacey.montgomery@mpssociety.org

Austin Noll (MPS IIIA parent)
austin.noll@mpssociety.org

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lisa.berry@mpssociety.org

Rebecca Dopheide (MPS IIIA parent)
rebecca.dophiede@mpssociety.org

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gordon.wingate@mpssociety.org

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matthew@mpssociety.org

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amber@mpssociety.org

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carol@mpssociety.org

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amy@mpssociety.org

Pathways Program Care Manager
Evelyn Fisher, MSS, MSc
evelyn@mpssociety.org

Development and Program Support
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bethany@mpssociety.org

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joseph@mpssociety.org

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leslie@mpssociety.org

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MPS & ML CLASSIFICATIONS

Mucopolysaccharidoses (MPS) and Mucolipidosis (ML) are genetic lysosomal storage diseases (LSD) caused by the body's inability to produce specific enzymes.

MPS I

MPS I H Hurler

MPS I S Scheie

MPS I H-S Hurler-Scheie
Enzyme / α-L-Iduronidase

MPS II

MPS II Hunter
Enzyme / Iduronate sulfatase

MPS III

MPS III A Sanfilippo A
Enzyme / Heparan *N*-sulfatase

MPS III B Sanfilippo B
Enzyme / α-*N*-Acetylglucosaminidase

MPS III C Sanfilippo C
Enzyme / Acetyl CoA: α-glycosaminide acetyltransferase

MPS III D Sanfilippo D
Enzyme / *N*-Acetylglucosamine 6-sulfatase

MPS IV

MPS IV A Morquio A
Enzyme / Galactose 6-sulfatase

MPS IV B Morquio B
Enzyme / β-Galactosidase

MPS VI

MPS VI Maroteaux-Lamy
Enzyme / (arylsulfatase B)
N-Acetylgalac-tosamine 4-sulfatase

MPS VII

MPS VII Sly
Enzyme / β-Glucuronidase

MPS IX

Enzyme / Hyaluronidase

ML II/III

ML II I-Cell

ML III Psuedo-Hurler polydystrophy
Enzyme / *N*-acetylglucosamine-1-phosphotransferase